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‘Buddy Pairs’: a novel pilot scheme crafting knowledge exchange between biomedical dementia researchers and people affected by dementia

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Abstract:

The ‘Buddy Pairs’ pilot project, launched at the University of Edinburgh, created opportunities for people affected by dementia (people living with a diagnosis and care partners) and dementia lab researchers to participate in knowledge exchange conversations through experiential lab tours. The primary aims were to raise awareness and understanding of current dementia research and its practices, as well as allow biomedical researchers to learn about the lived experiences and research concerns of those affected by dementia. This scheme found success by flipping normative ‘speaker-audience’ communication set-ups and foregrounding the expertise held by, and communication needs of, people affected by dementia.

Keywords:

Communication, dementia, knowledge exchange, lab researchers, lived experience.

Introduction

This project was an innovative Public and Patient Involvement (PPI) pilot scheme run at the University of Edinburgh which formed 'Buddy Pairs', between Scottish dementia research laboratories (labs) and people living with dementia (and their care partners). This scheme brought members of the public with lived experience of dementia into biomedical research labs for experiential tours to enable direct and informative knowledge exchange with researchers. The organization of this scheme is part of a growing interest in public engagement within dementia research contexts. For example, the *Dementia 2020 Challenge* invested £290M into the creation of Dementia Research Initiative (UK DRI) labs, which require the novel stipulation of significant public engagement by biomedical researchers. This project was also informed by Alzheimer Europe's position on the mutual benefit gained from involving people with dementia in PPI (Gove et al. 2017).

A cornerstone aim of this project was to promote constructive and collaborative conversations between researcher and lay partners within each 'Buddy Pair'. Our ethos was one of inclusivity and we worked to disrupt customary speaker/audience dialogue configurations in which the expert knowledge of researchers is highlighted over that held by people living with dementia and their care partners. Indeed, a number of the scheme's dementia researchers pointed out they had never met a person living with the condition they researched and were interested to learn about the feelings and perspectives of their Buddy Pair partners. Similarly, many of the lay members recruited were curious about 'what they do in there [the lab] all day' and see how dementia research funds were being put to use to devise a treatment or cure. Herein, we first discuss how the project was set-up to encourage inclusivity, before moving onto a detailing of what some of the experiential lab tours entailed and what they achieved. Lastly, we examine the feedback we received and future plans for the scheme.

Project Set-up

Research on communication in dementia contexts and building collaborations with people with dementia (Clarke et al 2018; Novak and Wilkinson 2017) has shown that language, the role of gatekeepers and rapport built within the research relationship are key to ensuring inclusive research practices. We incorporated these lessons into the set-up of the project by addressing the need for language sensitivity with participants with dementia within the scheme and thoroughly planning and testing tour itineraries, going through trusted gatekeepers during the recruitment phase, and working to build friendly rapport between the Buddy Pair lay partners and the scheme planning team, as well as their partnered researchers.

Much of the initial planning of this project included recruiting labs and participants from the public who would be keen to meet one another and indicated that they were amenable to helping shape the experience of this pilot scheme. Members of the public were recruited through the Centre for Dementia Prevention (http://centrefordementiaprevention.com/) registry and through in-person visits to dementia support services in the Edinburgh area. The scheme was pitched informally to community groups for people with dementia and carers, and interested individuals were spoken with one-on-one to understand their interests in and questions about research, mobility and communication circumstances, availability and transportation preferences, and comfort being in public spaces and speaking with strangers. This information was used to make a Buddy Pair match that supported both partners' comfort and ability to interact with one another. We also arranged transportation services on lay participants' behalf, in recognition that transportation difficulties are a significant barrier to people with dementia's participation in activities outside the home (Sanford et al 2018). While recruitment of lay participants was begun early in the project set-up phase, communication with care partners and people with dementia was maintained until initial tours could be scheduled. This helped establish a good rapport and kept both lay participants and the planning team apprised of any arising circumstances that needed to be taken into account to support participation in the scheme. Through these approaches, the pilot project team worked to create an atmosphere of inclusivity and open communication to promote lay participants' sense of ease and ownership in the scheme's activities.

A key part of the planning process was also a series of meetings held with the dementia lab researchers recruited to the project. All researchers, at all career stages, were invited and attended these meetings. Our rationale was that in encouraging the inputs of PhD researchers alongside more senior postdoctoral researchers and thus validating the discussion contributions of all attendees, regardless of seniority, an initial reordering of ideas about expertise, and those who held it, would be encouraged. The first of these meetings began with a presentation by the project coordinator, Lilian Kennedy about the aims and objectives of the project, namely that tours will be built on, and foster collaborative, constructive dialogue between researchers and people with dementia and carers. Many of the dementia researchers in the room had never, or did not currently interface with people diagnosed with dementia. A few expressed concerns about connecting with people with dementia and worries about how far 'progressed' some of the 'Buddy Pair' partner's dementia might be. Anticipating these concerns from initial recruitment conversations, the second half of the induction presentation centered on communication and language sensitivities that biomedical researchers should be aware of when working directly with people living with dementia. The relevance of embodied communication, the importance of particular terms, and speaking directly to people living with dementia, as opposed to care partners only, (Jenkins 2013; Kontos 2006, 2012; Kontos and Miller 2017) was covered to prepare some researchers about the varying verbal language or memory abilities of those who might be attending lab tours. It also instigated questions on the part of researchers and discussion about the ways in which people might communicate, show interest, express themselves or participate in conversation beyond coherent, verbal dialogue. One of the pertinent points we attempted to relay was that the conversations that took place over the lab tour need not be entirely focused on the subject matter at hand, i.e. the current dementia research being showcased, or be productive in a straight-forward learning outcomes capacity. Instead, friendly, open and patient rapport was an important goal of these initial Buddy Pair tours and perhaps the most important first-step toward participant retention and a knowledge exchange conversation in which people with dementia and carers felt their experiences and expertise was valid and appreciated.

In addition, the induction presentation made it clear that certain terminology, such as 'sufferer' and 'patient' could be stigmatising and impede the flow of conversation between researchers and people with dementia. Guidance for best practices in terminology use was drawn from best practice guides put out by the DEEP, the Dementia Engagement and Empowerment Project (https://www.dementiavoices.org.uk/deep-guides/for-organisations-and-communities/). In the induction meetings held with researchers, some asked why some long-winded terms such as 'person with dementia' or 'person living with dementia' was more conducive to conversation then the concise term 'patient'. It was explained that the term 'patient' in reference to the 'Buddy Pair' participants who had a diagnosis of dementia was inaccurate for the context of this scheme, and especially for the role they were asked to take in the tours. People with dementia were not visiting the clinical spaces as patients, but instead as equitable participants in the project. Researchers took this approach to terms on board and appreciated the value this subtle adjustment might add to building rapport and mutual respect when meeting and speaking with their Buddy Pair counterparts. Unsurprisingly, these terminology adjustments were points to which we returned often over the course of the project. For example, as 'patient' was a term to refer to people living with dementia, or any condition, in biomedical lab contexts where our researcher participants spent most of time, in comparison to public engagement lab activities. Discussion sparked by the concepts of embodied communication and terminology was used to instigate discussion and subsequent brainstorming about ways in which lab tours might be structured to capitalise on the rapport built through sensitive interactions.

Experiential lab tours:

After initial induction meetings with researchers, one-on-one meetings with individual lab groups were held to brainstorm ways to best showcase their research and interests in ways that were tailored to mobility, communication and sensory perspectives of their partners. Drawing from Latour's theorization of laboratory and biomedical research scientists as highly specialized technicians who create knowledge through procedures (1979), tours focused not only on the research topic of a particular lab, but also the particular research methods by which cutting edge

insight into dementia is produced. These focusses aligned with aims to reformulate typical presenter/audience dynamics as we sought to make tours an opportunity for lay Buddy Pair partners to be involved in a laboratory experiment as a means to relay the knowledge produced by, and aspirations of, the research itself. As such, the majority of the tour time was dedicated to moving through and interacting with lab spaces alongside researchers. By setting-up the tours in this way, people with dementia and carers were encouraged to ask questions about the knowledge produced by research and current research methods in reaction to what was being shown and discussed in the moment.

Rapport between Buddy Pair partners was built with a tea and biscuit conversation session at the start and finish of the lab visit. The use of PowerPoint slides or overly long biomedical descriptions of dementia were kept to a minimum during these sections to establish the informal nature of these tours, avoid over-taxing lay participants' attention, and encourage participants' comfort in asking one another questions. The informality and experiential framework also created opportunities for researchers to learn about the subjective experience of dementia, how people manage dementia day-to-day and what their concerns and hopes for the future are. Indeed, it was during these parts of the visit that Buddy Pair partners discussed the lived experiences of dementia most. As such, these tours sought to challenge notions that expertise about dementia lies only with academic or biomedical researchers, and showcase that people living with, or alongside, dementia possess a great deal of expertise about the physical, psychological, and social aspects of condition and on what research efforts should focus.

Turning to a lab tour formulated and hosted by the McColl lab group at the University of Edinburgh's Centre for Discovery Brain Sciences offers an illustration of how many of scheme's tours unfolded. The tour of this lab was led by researchers Michael Daniels (postdoctoral researcher) and Caoimhe Kirby (postgraduate researcher), under the advisement of Dr. Barry McColl. Lilian Kennedy met one-on-one with the junior members of this lab group to brainstorm and plan their tour programme. Both Michael and Caoimhe brought a great deal of enthusiasm to

the planning process. This was demonstrated by their initial desire to include almost every stage of an experiment they frequently ran in their lab and bring lay partners to a variety of laboratory spaces. Together, the planning group toured the various spaces of the laboratory, with Lilian taking timings of how long it took to slowly walk from each space and amount of time spent in each section discussing the element of the experiment demonstrated there, and the number of people, ambient sounds and noise usually present in each section. She took pictures and videos of each space and every lab process for reflection on Health and Safety and interest. In a discussion about the practicalities, Health and Safety stipulations, and ways to curate sustained interest during the tour, Michael suggested that certain materials for the tour be prepared beforehand in a 'Blue Peter' style of presentation, in which various stages of the experiment were planned in advance. This meant that when one phase of the experiment had been 'completed' by the lab tour team, it could be put away and the next step's materials, which might normally take a week to mature or prepare, could be pulled out and the experiment continued. In so doing, the tour itinerary condensed an experiment that required two months to run into a 40-minute tour through a series of four key steps of the experiment.

Each step showcased the innovative scientific approach and findings of the McColl lab as well as the technical craft of research through visually interesting displays that also allowed Buddy Pair partners to get involved in the experiment in safe ways. For example, Figures 1A-F shows Michael showing the mouse brains used in their experiments before he went on to display the dounce tool (which resembles a mortar and pestle) used to homogenize matter, such as a mouse brain into a single cell solution. Next, Elisabeth (one of the buddy participants) practiced her pipetting technique (with saline solution). These actions were put into context through Michael and Caoimhe's explanations of the ways in which mouse brains are used in the lab to test their response to inflammatory stimuli, which the group then viewed under the microscope. Through this experiential series, the researchers were able to showcase how their experiments help to reveal the ways in which the immune system can be involved in the protection, or the pathology of, dementia.

While the researchers provided context and background to each step of the tour experiment, the set-up of this tour, and others in the scheme, allowed questions and interest shown on the part of the lay Buddy Pair partners to instigate much of the discussion at each section. It also allowed more informal connections between the work of researchers and the past experiences of the lay Buddy Partners to be drawn. For example, Elizabeth and Bobby remarked on the similarity of skills and timing needed to create the various solutions for an experiment to that of cooking, and drew connections between the skills needed to work on independent research within a larger collaborative research lab to that of Bobby's experience building constructive business relationships with clients. Further, the Buddy Pair partners did not only discuss the biomedical aspects of the tour's subject matter, and during the approximant 10 minutes spent at each experiment stage, lay partners also spoke about their dementia management strategies, and what the condition of dementia had, and had not, changed in their life. Researchers asked questions about experience of getting a diagnosis and their partners' insights into what they felt were the most pertinent elements that 'makes dementia, dementia'. The set-up of the scheme's tours stand in contrast to a set-up in which 'experts' tell their audience about their methods and findings in a format that only encourages questions at the end of a presentation. The strength of the Buddy Pair approach lies in its aim to build rapport and real-time knowledge *exchange.*

Project feedback

The scheme was determined to be a success based on all research and lay person participant's desire to take part in the scheme again (should roll-out beyond the pilot stage be made possible), and positive feedback which highlighted the learning made and sense of connection forged to their buddy pair. The scheme ended with a 'Thank You' Final Feedback meeting and lunch. The majority of researcher partners and lay partners were able to attend and enjoyed reconnecting with their partners. The feedback collected from lab groups and care partners and people with dementia was presented and discussed with the group at large. The main successes of the project detailed by participants were its smooth logistical planning that made 'it easy to come along' for lay

partners in the scheme, flexible planning style 'so we could still come after we had to cancel our first appointment' and 'could slow down and skip one part because she (Buddy Pair partner with dementia) was getting a bit sore on her feet.' Lay participants also highlighted that the researchers were friendly, enthusiastic about their work, and communicated their research in a way that made the intricacies of their work understandable. Researchers highlighted the value of thinking through and explaining their research to a lay audience on their communication skills more generally, and senior researchers described their satisfaction that younger members of their labs were gaining this experience earlier in their research career than they had. Their feedback comments highlighted the importance of Public Patient Involvement efforts in their own endeavors, shifting perceptions that such efforts were primarily a type of charitable outreach. Many of the researchers also expressly commented that in hosting these tours they were 'reminded of why you do this [the research] in the first place – it was helpful to talk to people who really care about what you're doing…that you want to help.' Five out of the seven care partners in the scheme's Buddy Pairs described the effects the tour had had on their family member with dementia after the tour ended. They described their family member 'talking about everything we'd seen that afternoon the next day', and many were impressed by the retention of information they showed. Care partners also spoke about their family members 'talking with the cab driver who took us home – he [the cab driver] asked about what we had been doing, and I was so impressed, [Buddy Pair partner with dementia] told him about the big microscope we'd seen, and even better, when we spoke to our grandson later, he [Buddy Pair partner with dementia] told him all about the tour as well, talking about the building we had been in.' All Buddy Pair partners highlighted that they had 'fun' and 'really enjoyed the afternoon' and were interested in participating in another tour. The sum of these feedback comments illustrate the successes in learning and rapport building the tours achieved, as well as the value these tours held for lay partners and researchers after the tour ended.

There are also areas for learning and improvement based on tour feedback. While lay Buddy Pair partners underscored the pleasure they took in the back-and-forth style of dialogue throughout the tour and care partners' commended 'their [researchers'] patience with everything she [partner

with dementia] was telling them they should be doing', others made remarks indicating a feeling that their contributions to the discussion had were not as valuable as those of the researchers. For example, I was told 'I'm not sure how much we could actually add – it was nice that they wanted to hear about our side of things, but I don't know how important what we could say was' and 'they're [the researchers] are doing such impressive things! I know Mom [lay Buddy Pair partner with dementia] because I'm with her taking care of things most days, but not sure how useful that is to them [the researchers]. This was a surprising finding, and points to assumptions the planning team made about lay partners' views about the value of their own perspectives and empirical knowledge. Remarks such as these show that there is a need to address these feelings to support equitable knowledge exchange in future phases of this scheme. This might include holding an informal meeting with lay participants before tours in the style of those held with researchers to elucidate more clearly the aims of the project as well as its founding ethos of inclusivity and respect for varied perspectives in building the Buddy Pair partnerships.

Conclusion

Due to the positive feedback and growing interest in the scheme, as well as a growing list of interested lay persons with dementia and their care partners interested in participating, we plan to build on this pilot scheme. This will include the induction of additional research labs at the University of Edinburgh, and the implementation of the scheme at the University of Dundee, with an eventual expansion of the scheme across other Scottish dementia research labs. Funding for this endeavor is currently being sought.

A wider rollout of this scheme will take forward a majority of the same recruitment, and logistical setup to ensure that the success of the pilot scheme is replicated. Emphasis on approaching tours as a multi-faceted endeavor centred on learning, as well as relationship building will be key. This provides a unique opportunity for people with dementia to be involved in discussions with

researchers about basic research and early-stage project plans in ways that benefit both parties, such as: greater awareness of the hard work underway to find treatments for dementia, and direct feedback to strengthen researchers' lay summaries and outreach/engagement proposals.

Importantly, this type of setup up allows for researchers to challenge their views of PPI as a kind of charity outreach, and lay participants as only recipients of knowledge. This pilot scheme also created a unique opportunity to instigate new research approaches and questions among dementia researchers through hearing from people with dementia and carers about their experience of the disease and their concerns around research and treatments. The planned roll-out of this scheme across additional sites will maximize this potential value and future expansion plans hope to show that this personal experience between participants and researchers will lead to new insight into dementia research.

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A

B

C

D

E

F

G

Figure 1: Example of a Dementia Buddies experiential lab tour.

A-C: Demonstrating and then preparing for a live practical experiment, suitable for the buddy pair's abilities. D-F: Performing the experiment and analyzing findings. G: Group photograph at the end of the experience. *Permission to use photographs have been given by all those included in the pictures.*